



## Recommendations

The participants of the Roundtable Conference developed the following specific recommendations.

### Outreach

#### *Collaboration*

NIH and IHS should collaborate on research training activities to maximize and coordinate their individual efforts and to take advantage of each other's strengths.

- The potential resources available in the American Indian/Alaska Native (AI/AN) community should be more fully engaged by the NIH through active consultation with, and outreach to, Tribal governments and the National Indian Health Board.
- The NIH should recognize that as the representatives of sovereign nations, Tribal governments are a unique resource for gaining access to and encouraging student development.

#### *Site-Visits*

NIH representatives should seize the opportunity of reaching out to the American Indian/Alaska Natives community through on-site visits and develop programs that would bring NIH funded investigators in all disciplines to the American Indian/Alaska Natives community because:

- Unlike any other minority group in the U.S., American Indian/Alaska Natives reside in rural locations, far from academic institutions.
- The benefits include educating both tribal leaders and students in the purpose and value of biomedical research and career opportunities.

- NIH representatives can gain an appreciation for the barriers that exist for students interested in biomedical research and be able to better design research training programs.
- The value of the trust that could come from such interactions would far outweigh the costs.

#### *Information Dissemination*

Create and utilize various media to communicate information directly to American Indian/Alaska Natives communities, organizations and Tribal Colleges; e.g. web-site, listserve, newsletter, mailings. Send grant information, requests for proposals, and job announcements directly to tribes and key organizations (e.g. SACNAS, AAIP, AISES, AI/ANRN). Disseminate general information about NIH through Tribal Colleges, American Indian/Alaska Natives organizations.

- Explain NIH structure and focus of individual Institutes, Centers and Offices.
- Describe funding and training opportunities such as the Minority Supplement program.
- Clarify how to access relevant NIH resources and programs such as the MORE programs and loan repayment opportunities.
- Develop grant training programs, or NIH staff activities, that will train, guide and advise American Indian/Alaska Natives researchers, organizations and governments on how to successfully participate in the NIH grant process.
- Share information on the peer review process and how to insure that applications are reviewed in their proper context and by appropriate reviewers.

- Provide monographs of the work of individual Institutes and Centers, such as the National Cancer Institutes', *Native Outreach: A Report to American Indian, Alaska Native and Native Hawaiian Communities and Documentation of the Cancer Research Needs of American Indians and Alaska Natives*.

#### *American Indian Liaison Office*

Develop a liaison office or position for underrepresented minorities within the Office of the Director with a representative or ombudsman whose specific and sole focus is on American Indians/Alaska Natives.

#### *Recruitment*

Institute aggressive recruitment strategies of underrepresented minorities such as used by industry to increase American Indians/Alaska Natives staff at NIH. Begin by expanding summer outreach activities that include workshops and courses on research issues and the grant funding process.

#### *Ongoing Dialogue*

Continue to dialogue with representatives from American Indian/Alaska Native communities; following up on the work done at this preliminary meeting.

### **Grant Application Process and Approval Procedures**

*(for research proposals involving American Indian/Alaska Native communities)*

#### *Response Time*

Insure that the timeline from the release of RFA, RFP, or PA to the submission deadline is a minimum of three months or preferably longer, in order to insure that Tribal Council and/or Tribal IRB (when appropriate) approval can be obtained.

#### *IRB Approval Process*

If legislative or fiscal constraints require a short interval between the publication of an initiative in the NIH Guide and the application receipt date, modify the IRB approval process so that the IRB process has begun, rather than being completed, prior to the grant review.

#### *Minimum Grant Period*

The normal grant period for awards involving American Indians/Alaska Natives communities should be five (5) years to allow for the added time needed to plan and implement the research program.

#### *Require Community Involvement*

Mandate American Indians/Alaska Natives community involvement in the grant proposal development process.

- Require certification that the local community has been notified of pending grant proposals.

- When appropriate, recognize Tribal Sovereignty by requiring review by the Tribal IRB, Tribal Health Board and/or the Tribal Council.
- Require Principal Investigators to present proposals to the Tribal IRB/Tribal Health Board and/or Tribal Council for review in person.
- Review Participation: Include American Indians/Alaska Natives ad hoc reviewers, for all grants involving American Indians/Alaska Natives communities, who have knowledge of special issues related to American Indians/Alaska Natives research and research training.

#### *Consider Geographical Expenses*

Allow for higher travel budgets on studies to be conducted or involving rural American Indian/Alaska Native communities. Review panels should be aware of the expenses involved for research and research training staff to travel to meet with the local communities, or for representatives or students from the communities to travel.

#### *Local Capacity-Building*

Make explicit requirement for local capacity-building in extramural research grants or intramural research programs working with native communities.

- Involvement of community in developing and monitoring programs
- Supplement existing programs to train community members to be active participants in the research activity
- Recruitment of students as summer interns
- Outreach teaching in local schools

## **Working with Non-traditional Grant Recipients**

### *Mentoring*

Provide funds to NIH research grant investigators to participate in mentoring activities at annual meetings of student-oriented organizations, such as the American Indian Science and Engineering Society (AISES), the Society for Advancement of Chicanos and Native Americans in Science (SACNAS), the Association of American Indian Physicians (AAIP), the American Indian/Alaska Native Research Network (AI/ANRN) and the American Indian Higher Education Consortium (AIHEC) Meeting. This could be done by including travel for the PI and student on minority supplements.

### *Recruitment*

Utilize non-profit student organizations to locate and recruit students for internships and scholarships. A useful model is the NINDS partnership with SACNAS for the identification of applicants for predoctoral fellowships in the neurosciences.

### *Research Training*

Offer more research training grant opportunities for non-traditional grant recipients such as non-profits and Tribal health programs.

### *Partnership Building*

Promote partnerships between non-profits and community programs to develop training and internship opportunities; e.g. SACNAS/University of Puerto Rico, Humaco, and the Summer Institute in Mathematics for Undergraduates (SIMU).

## Working with Tribal Colleges

### *Expand Opportunities*

Expand and enhance opportunities to bring in extramurally funded investigators from NIH and IHS to increase capacity of tribal colleges, and to promote research, research alliances and research training.

### *Tribal College Outreach*

Reach out to Tribal Colleges so they are aware of programs supplying state-of-the-art equipment, resources, and training for competitive grant writing to increase capacity to conduct research and training.

### *Faculty Outreach*

Develop working relationships with Tribal Colleges so they are aware of opportunities for individual Tribal College faculty to be interns for paid summer NIH programs.

### *Support Summer Internships*

Promote and support summer internship programs organized by AISES, WINS and other non-profit organizations, that carry out support for individual students, of two-year duration, at NIH and NIH-funded institutions to promote continuity and commitment.

### *Partnership with Tribal Colleges and other Institutions*

Encourage large research institutions, and NIH researchers who are doing research in American Indian/Alaska Native communities, to partner with Tribal Colleges, for example teaching via teleconferencing.

## *Community Based Research*

Provide opportunities to Tribal Colleges for funding new investigator programs, and for supporting researchers who choose to work in local communities.

## Mentoring and Training for Students, Young Faculty and MD's

### *Community Based Summer Internships*

Fund meaningful summer internships within local communities where students can have a positive impact, present findings and potentially continue to work in that community.

### *Alternate Community and Institution Training Experience*

Initiate alternative education programs where students work one year in the community and one year with NIH or IHS (IHS should consider additional partnerships with CDC in epidemiology research).

### *Sanctions for Non-compliant Institutions*

Put substantive Consequences into place for NIH-funded institutions that fail to comply with grant requirements of recruitment, retention and graduation of underrepresented minority students.

### *Develop American Indian-Specific Field Sites*

Develop field sites, such as the NIDDK Phoenix Diabetes research center, as resource and training centers for students.

- In consultation with the American Indians/Alaska Natives community, hire and train staff to mentor students in a culturally appropriate manner.

### *Develop a Data Bank*

NIH should fund a meeting, bringing together scientists and student-oriented non-profits, to create a linked or centralized data base of mentors, students and mentoring resources and programs nationwide.

### *Develop Strategies for Older Students*

Develop targeted re-entry programs for older American Indian/Alaska Native students to enter the sciences or transition into the research arena.

### *Research Training for Indian MD's*

Support regionally based training programs on research methodology for American Indian and Alaska Native physicians, dentists, and nurses.

### *Utilize the Interagency Personnel Act*

Be creative in the use of the Interagency Personnel Act (IPA), such as placing a university person with NIH; an NIH person placed with university in field, or with Indian organizations or communities, for mentoring, recruitment, and training/technical assistance.

### *Career Development Opportunities*

Create new research career development award programs (e.g., K02 and K24) for American Indians/Alaska Natives researchers to assist in the transition from post-doctoral, to junior faculty and tenured faculty positions.

### *Expand Cancer Research Training*

Expand the Native American Cancer Researchers Training Program into additional research areas (i.e., diabetes and heart disease).

### *Expand Opportunities for NIH Graduates*

Provide support for graduates of NIH training activities, such as the Native American Cancer Researchers Training Program, so they may initiate pilot studies (similar to Extramural Associate Program) that would enable new investigators to generate the pilot data needed for K03, R25 or other funding mechanisms.

### *Pre-college initiatives*

#### *Support K-12 Initiatives*

Reexamine NIH mandates, adding K-12 programs to the funding priority.

#### *Support Science and Math Initiatives for Indian Youth*

NIH and IHS should consider that the future health of Indian children must include a solid science and math education and, if necessary, build such a mandate into their reauthorization acts.

### *Understanding/Respecting American Indian/Alaska Native Culture*

Although the emphasis of the meeting was on research training, several issues pertaining to research in American Indian communities were prominent throughout the discussion. The following recommendations relate to improving the credibility of researchers among Indian tribes.

#### *Improving the Relationship with Tribes*

Key members of IHS and NIH staff should work with the White House Domestic Policy Council on American Indian Affairs, the NSF and other agencies to develop respectful policies in regards to American Indians/Alaska Natives communities, particularly regarding genetic or traditional practices research.

### *Implementation of Tribal Consultation Policy*

NIH should participate in the Tribal Consultation Process.

- Tribal government approval should be required for any research involving the tribe.
- NIH should include tribal officials on the peer review sections that review tribal grants.
- NIH intramural research activities, involving specific tribes, must also obtain tribal IRB approval.

### *Publication of Policy*

NIH should develop and publish their policy statements regarding intent of research in American Indian/Alaska Native communities, particularly in regards to genetic research, cell line repositories, pharmacogenetics research and research on traditional medicine practices. IHS should publish their policy statements regarding their intent of research in American Indian/Alaska Native communities, particularly in regards to genetic research, cell line repositories, pharmacogenetics research and research on traditional medicine practices.

### *Develop and enforce policies on human samples*

Mandate appropriate collection, storage, use and disposal of human genetic tissue, and blood samples in American Indians/Alaska Natives studies.

- Samples taken for specific study need to be closed and not further used at the end of the specified grant period.
- Tribally approved, culturally appropriate techniques for sample storage and disposal should be required; the Principal Investigator should get instructions for this during proposal review process.

- NIH should develop a protocol for addressing researchers who violate agreements regarding disposal and/or secondary use of specimens.
- There should be a NIH policy statement regarding intramural and extramural use of samples in secondary studies. IHS utilizes the IHS IRBs for this purpose.
- Require active participants' consent for secondary use of genetic samples, the use of passive consent is not acceptable.

### *Reauthorization of the Indian Health Care Improvement Act*

The Indian Health Care Improvement Act should be reauthorized with the inclusion of specific provisions addressing American Indian research standards and interagency linkages.

### *Accountability and Responsibility of Researchers*

Research institutions and intramural NIH researchers, who are doing research in American Indian/Alaska Native communities, must be held responsible for their work by the funding institutions and must be done in cooperation with the American Indian communities involved.

### *Interagency Coordination of Research Policies*

Share the recommendations of this Roundtable with other agencies including NSF, DOD, DOE, DOI, etc., that conduct research in American Indians/Alaska Natives communities; urge them to adopt a Tribal Consultation policy.